



## Illinois HIV Integrated Planning Council (IHIPC) Meeting Minutes

June 28, 2019, 8:30 am – 1:30 pm

8:30 am: Committee breakouts: Discuss IHIPC Input/Reach Consensus on Proposed 2020 Changes to Prioritized Populations, Risk definitions, and I&S Guidance  
Each IHIPC committee conducted in-person meetings before the full body IHIPC meeting.

9:15 am: Welcome; Introductions; Review of agenda/meeting objectives; Moment of silence

Co-Chairs J. Nuss and M. Benner welcomed all members/guests to the meeting. The Co-Chairs reviewed webinar instructions and housekeeping instructions. Following this, the group was led in a moment of silence for all people living with HIV past and present and for all those working to end the epidemic in Illinois. All in-person participants introduced themselves, and webinar participants were announced. The Co-Chairs reviewed the meeting objectives, meeting agenda, and the IHIPC concurrence checklist.

9:30 am: Presentation/Discussion/Vote on Proposed 2020 Changes to Integrated Plan Components (30 minutes)

After discussion at its Day 2 committee meeting, the Epi/ NA Committee announced that it was moving forward with its motion to accept recommendations presented on Day 1 for the 2020 Priority Populations and 2020 Risk Group Definitions. Voting members were provided with copies of the draft 2020 prioritized populations document.

Vote: At 9:45, the motion was made by N. Holmes and seconded by S. Fletcher to accept the 2020 Priority Populations as recommended and presented by the Epi/ NA Committee on Day 1. The motion carried with 31 “yes” votes, 1 “abstain” vote, and 3 members not present.

Vote: At 9:49, the motion was made by J. Charles and seconded by J. Filicette to accept the 2020 Risk Group Definitions as recommended and presented by the Epi/ NA Committee on Day 1. The motion carried with 23 “yes” votes, 8 “no” votes, 1 “abstain” vote, and 3 members not present.

10:00 am: Presentation/Discussion: Cluster Detection and Response Plan

F. Ma and C. Hicks presented on behalf of C. Ward on IDPH’s HIV Cluster Detection and Response. The following topics were reviewed: key terms for cluster detection and response; processes in which cluster analysis is used to help focus HIV prevention efforts; information about how groups of related infections are identified; time-space clusters; how to prioritize and respond to groups of related infections; how Illinois protects HIV information during cluster detection and response; and how community members can participate in cluster detection and response activities. Please see the presentation slides for more detailed information.

Discussion:

Q: I know that a genotype test is performed to determine drug resistance at diagnosis. Is it correct that genetic testing is done as a secondary/ compliment test to drug resistance testing? This testing helps to identify related cases, or clusters. Many HIV criminalization groups have been meeting around the nation regarding this topic. Although there is no direct evidence of the transmission pattern of the HIV (i.e. it cannot be determined who passed HIV onto others), is it not true that information could be used as circumstantial evidence against a person living with HIV if a person believed they acquired the virus from a particular person? It is a concern for people living with HIV that privacy is not respected and that this information is being shared without consent. This seems like a repurposing of health data. Only a few countries (the United States and Canada) are using these methods in surveillance efforts due to ethical concerns. With that said, what is being done by IDPH to protect our information? What kind of authorization methods are being used to ensure that people living with HIV understand and consent to these activities, especially when contacting partners in as part of a cluster response effort?

A: C. Hicks responded: Yes, the main purpose of a genotype test is to test drug resistance. The same sequencing that is identified for the drug resistance testing is used for genetic testing. The AIDS Confidentiality Act includes many safeguards for protecting HIV information. Drug resistance testing is done to better the individual's health, and that information is also used to better community health by identifying and allocating specific, impactful resources/efforts when clusters occur. The concerns about repurposing of data and criminalization laws are very important and are very seriously considered by IDPH when protecting health data. This HIV section is continuing to make policy changes to ensure that health information is completely safeguarded. To date, there has never been an incident in which there was a breach in HIV data to legal entities. The Attorney General and the IDPH lawyers partner with the HIV Section to ensure that the information is never illegally released/abused by any legal or law enforcement entity.

Q: Has there ever been a time that IDPH was subpoenaed to release personal HIV health information in a prosecution case?

A: C. Hicks responded: I am not aware of this ever happening. C. Ward might better able to answer that question.

Q: I believe that there are lawyers out there that will push IDPH for this information in specific cases. When agencies tell clients that their information is totally confidential, it seems deceptive to repurpose information for cluster response. It jeopardizes the trust that clients have in services organizations. For example, what if a person is called to be notified of their relation to a cluster but they have only had one partner? They now automatically know that that one partner exposed them to HIV. The person living with HIV has now lost all confidentiality. If the partner acquires HIV, they could work with a lawyer to use genetic testing information to support their case. Political climates are not stable and could change the way that this data is protected by IDPH in the future.

A: C. Hicks responded: In regard to partner notification, there is really no difference between how partner service and cluster detection procedures would play out in this scenario.

C: There is a difference because of consent and the repurposing of data for cluster detection purposes. The client's consent is for HIV testing, not for their DNA. Some clients really do believe that the government is after their DNA. By not being completely transparent about genetic testing, we are making this real for clients, especially for clients who only have one partner. Consent remains a huge issue for both people living with HIV and their partners.

A: C. Hicks responded: The genetic testing data only examines a very limited portion of the HIV virus's DNA to determine clusters. It is impossible to use this information to make conclusion about transmission patterns. In order for partners to be notified of their potential exposure to HIV, the client must identify/ name them for testing. When this occurs and the partner is notified, the name of the client is never disclosed. This procedure is followed in partner services and in cluster response. In a cluster response, the local health department never receives all of the names of the people living with HIV in the cluster, but only those relevant to their jurisdiction. If contacted, people living with HIV have the right to not provide information about partners and to decide not to pursue services like linkage to care that might be offered to them through cluster response. Additionally, information about partners whose HIV status is unknown can only be collected when they are voluntarily identified by people living with HIV in the cluster. The consent to contact these partners comes from the person living with HIV who voluntarily identified them.

C: As a person who has done disease investigation, I can say that during clusters, I was only ever informed of the need for a partner service notification and the partner's corresponding contact information. I was never told the name of the person living with HIV who identified them. Many named partners were surprised by the visit, and they also have the right to accept or decline testing services. All of this was done in a confidential manner with no issues. As public health professionals and advocates, we need to keep in mind that our job is to protect the health of the community. This must be balanced with consideration for personal well being of clients. I will share that I once had a client who was being pursued legally by a partner who believed the client had exposed them to HIV. At the time, it was determined that the law does state that records can be given to a judge in a sealed manner. A State Attorney took the case at that time and handled it appropriately.

C: I want to remind everyone, when a person living with HIV goes to their medical provider for services, they are allowing their medical provider to share information for surveillance activities under HIPAA. It's a part of federal law, which supersedes state laws. People need to know that when they sign HIPAA releases, they are consenting to use of information for surveillance activities.

Q: I have a scenario that I would like to ask a question about. Say there is a cluster that breaks out, and a partner is contacted by the LHD. If the partner has only had contact with one person and knows who exposed them, they might hire an attorney to seek a law suit for harm or endangerment. I trust IDPH protects the information, but I don't trust that there will not one day be a lawyer who finds a way to force IDPH to give out information as circumstantial evidence.

A: C. Hicks responded: In this scenario, the person who would be trying to seek a law suit would automatically know who they acquired the disease from at their HIV diagnosis. Cluster response information would not be needed for this person to try to pursue a lawsuit. Even if a lawyer tried to get this information, they would not be able to.

Q: Does Prevention need to more thoroughly examine/do a better job of clarifying what molecular surveillance and clusters are to clients seeking services? This might help with concerns around consent. Even explaining general surveillance more thoroughly might be helpful for clients.

A: C. Hicks responded: If someone is tested at an IDPH funded site, that information is in the testing consent. Legally, we could just get an oral consent, but we wanted to make sure that people had access to it in plain language. Hopefully test counselors are explaining this thoroughly as well. For non-IDPH testing programs,

clients may or may not get good or clear information about this. In almost all cases, they will sign a medical release, but the complexity of those releases may vary and are unknown to IDPH. We could look into implementing a structural intervention that better educates the public on confidentiality.

Time for discussion concluded. J. Nuss suggested that an additional meeting/webinar should be conducted to continue this specific conversation. It was also suggested that legal representation should be on the call to answer technical questions. The Surveillance Unit will be tasked with scheduling and announcing this additional meeting. J. Nuss will make sure the information is disseminated to IHIPC members, client reps, and interested community stakeholders.

#### 10:45 am: IHIPC Membership Demographic Survey Analysis/Membership Gap Analysis for 2020 Recruitment/Opening of 2020 New Membership Cycle

M. Andrews-Conrad presented on the IHIPC Member Gap Analysis and 2020 New Membership Cycle. First, the membership gap analysis was reviewed (i.e. a weighted analysis of HIV prevalence (50%) and incidence (50%) data by transmission category and race was compared to the self-identified demographic information of current IHIPC members). Other considerations for the membership gap analysis were also identified and included personal/professional expertise categories (as listed in the bylaws) and regional representation. Based on these categories, the following were identified current gaps/priorities for new member recruitment and selection:

- People from Region 1
- Young adults (aged 18-24)
- People who are Black, Hispanic, or identify as an “Other” minority race, specifically:
  - Black people representing MSM and/or PWID
  - Hispanic people representing MSM and/or PWID
  - People of “Other” race representing MSM

Lastly, components of the membership application and the membership selection process were reviewed. It was announced that applications for 2020 IHIPC membership will be accepted now through 9/15/19.

#### Discussion:

Q: When this planning body was formed, we had looked at other planning bodies to shape the bylaws and procedures for membership. My concern is that current members work for agencies and can represent their agencies in this way. What about people who are unaffiliated with an agency and are community members? How can the group get our input if we are not sitting at the table? I have been on CAHISC, and we have always had a policy to have 33% of our members be unaffiliated community members.

A: M. Andrews-Conrad responded: I would like to clarify that regardless of affiliation with an agency, all IHIPC members come to the table to represent the communities that they serve and/or personally represent. The IHIPC also welcomes all community members to apply for membership regardless of their current affiliations. I also want to clarify that there are differences in the procedures for CAHISC and IHIPC as they are differing RW Part A and B planning bodies, respectfully. Although the IHIPC does not have a goal for unaffiliated members, everyone is encouraged to apply and people living with HIV are engaged in the process through membership, planning group meetings, and other activities.

A: J. Nuss responded: Yes, CAHISC requires a certain proportion of unaffiliated members because the planning group makes decisions about resource allocation for care services for the EMA. The IHIPC does not do this for the state. Community input is important, needed, and collected from many people beyond IHIPC members through a variety of needs assessment activities and community engagement meetings.

A: The Membership Committee is working on recruitment strategies for the coming year to make sure that membership gaps can be filled. None of these goals prioritize either affiliated or unaffiliated members, but there is a need for membership to have a certain skill set in order to participate and bring voices to the table. Currently, the Membership Committee would like to look into recruiting at rehabilitation facilities, schools, re-entry organizations, etc. We ask that everyone helps us to meet these goals and disseminate information about membership. We will keep working to do our best as a committee.

C: Please change the term youth to young adult.

Q: Can young adults apply from any region? Do we explicitly target transgender people or non-binary people for membership?

A: J. Nuss responded: Yes, young adults can be from any region. The IHIPC bylaws also prioritize for voting membership a representative of the transgender community.

Q: Thank you, Membership Committee, for this information. I also think there is a need to prioritize unaffiliated members. This was discussed last year but did not move forward. Just because we are not required to have unaffiliated members does not mean that it is not important. In the presentation, it was noted that people

identified professionally or personally with certain transmission categories. Do we have data that shows how many members personally represent these communities? People with these lived experiences have perspectives that need to be considered in planning and should be prioritized as members on the IHIPC.

A: M. Andrews-Conrad responded: We collect information on IHIPC members' personal representation of transmission categories, but that information isn't shared for confidentiality reasons. We include all members in the gap analysis, so that is why we ask them to select one group that they either personally or professionally most represent. The scoring matrix used for the selection process prioritizes people who personally identify with one of the transmission categories by giving them a higher score for that criteria on their application. It also prioritizes people living with HIV or people who have significant relationships with people living with HIV.

Q: I would like to ask the Membership Committee to consider designating a certain number of PLWH membership positions for unaffiliated members.

A: Thank you. If there are more comments/concerns, please also fill out the meeting surveys as the Membership Committee reviews those after each meeting.

#### 11:15 am: Presentation/Discussion: Policy/Legislative Update

A.Singh presented the AFC June Policy Update. Updates on the following bills were presented: HB 2259 - the Medicaid Drug and Therapeutics Board Transparency Bill; HB 2665 – the Youth PrEP Bill; HB 465 - Copay Accumulators; and SB 132 – Medicaid Omnibus Bill. Information about the state's FY20 budget relevant to HIV related services was also shared. Please see the presentation for more information.

There was no discussion on this topic at the meeting.

#### 11:45 am: Working Lunch: Present an Overview of HIV Continuum of Care Health Disparities Root Cause Analyses Project

J. Nuss reviewed the HIV Care Continuum Root Cause Analysis Project in which the following steps have been completed:

- Step 1: Engage in conversations with planning group members and community stakeholders to identify priorities: low utilization of PrEP among people of color; lower rates of viral suppression among people of color; and lower rates of linkage to care among youth.
- Step 2: Identify and explore factors that influence or control prioritized disparities.
- Step 3: Acknowledge the impact of systemic policies and practices to explore the root causes ( as displayed in fishbone diagrams).

Participants were then charged with completing Step 4 of the process: To use the planning group and community stakeholder to actively inform decisions about or develop plans to address the root causes of each disparity. To achieve this, participants were instructed to review the barriers listed in the fishbone diagrams, and to then identify tangible solutions for each barrier. Webinar participants were instructed to do this on their own, and in-person participants were assigned to complete this activity in breakout groups. Each in-person breakout group focus on one disparity. Breakout groups were instructed to take notes and to identify the top 1-2 strategies in each category.

There was no further discussion/questions about the activity.

#### 12:30 pm: Breakout Groups: Review Root Cause Analyses Cause/Effect Diagrams and Identify Tangible Strategies to Address the Disparities

In-person participants broke out into three groups to complete the activity described above.

1:15 pm: Public Comment Period/RECAP- There were no requests for public comment at the meeting. Participants were reminded to complete the meeting survey, and IHIPC members were reminded to submit travel vouchers as applicable.

1:30 pm: Adjourn- The meeting adjourned at 1:30 pm.

#### 2019 Illinois HIV Integrated Planning Council (IHIPC) Vote Log: June 28 Meeting

Member Name	Member Type	Date: April 26, 2019 Time: 5:00 pm	Date: June 28, 2019 Time: 9:45am	Date: June 28, 2019 Time: 9:49am	Y: In favor; N: Opposed; A: Abstain; X: Absent or No vote cast/received TS: temporarily suspended
		<b>Motion 1:</b> A motion was made by Janet Nuss on 4/19/19 at 8:19 am and seconded by C. Tucker at 9:36 am to adopt the agenda for the June 27-28, 2019 IHIPC meeting as approved by the Steering Committee. The motion was sent to the full IHIPC at 1:12 pm on April 19, 2019. Members were given until 5:00 pm on April 26, 2019 to submit their votes.	<b>Motion 2:</b> A motion was made by N. Holmes and seconded by S. Fletcher to accept the 2020 Prioritized Populations for Targeted Prevention Services as recommended and presented on behalf of the IHIPC Epi/NA Committee.	<b>Motion 3:</b> a motion was made by J. Charles and seconded by J. Filicette to accept the 2020 Risk Group Definitions for the Prioritized Populations as recommended and presented by the IHIPC Epi/NA Committee.	
IHIPC Voting Members					

Benner, M.	Voting	Y	Y	Y
Bradley, W.	Voting	Y	Y	Y
Charles, J.	Voting	Y	Y	Y
Choat, L.	Voting	Y	Y	Y
Crause, C.	Voting	Y	Y	N
DeLaFuente, J.	Voting	X	X	X
Dispenza, J.	Voting	X	X	X
Erdman, J.	Voting	Y	Y	Y
Filicette, J.	Voting	Y	Y	Y
Fletcher, S.	Voting	TS	Y	Y
Frank, S.	Voting	Y	Y	Y
Gaines, M.	Voting	Y	Y	Y
Guzman, L.	Voting	Y	Y	Y
Hendry, C.	Voting	Y	A	N
Holmes, N.	Voting	X	Y	Y
Hoots, C.	Voting	Y	Y	Y
Hunt, D.	Voting	X	Y	Y
Johnson, R.	Voting	Y	Y	Y
Jones, S.	Voting	Y	Y	N
Laskowski, C.	Voting	Y	Y	Y
Lewis, K.	Voting	Y	Y	Y
Maginn, M.	Voting	Y	Y	Y
Meirick, A.	Voting	X	X	X
Meyer, L.	Voting	Y	Y	N
Nuss, J.	Voting	Y	Y	Y
Olayanju, B.	Voting	X	Y	Y
Paesani, T.	Voting	Y	Y	Y
Rehrig, S.	Voting	Y	Y	N
Roeder, L.	Voting	Y	Y	Y
Stevens-Thome, J.	Voting	Y	Y	N
St. Julian, S.	Voting	X	Y	N
Tucker, C.	Voting	Y	Y	Y
Williams, M.	Voting	X	Y	A
Williamson, M.	Voting	Y	Y	Y
Zamor, S.	Voting	Y	Y	N
Type of Vote: Hand Count, voice, electronic		electronic	voice	voice
Results: Carried/Defeated		carried	carried	carried
Results: Vote Count		<u>26</u> in favor , <u>0</u> opposed, <u>0</u> abstentions, 8 members absent or "no vote cast/received"	<u>31</u> in favor , <u>0</u> opposed, <u>1</u> abstention, <u>3</u> members absent or "no vote cast/received"	<u>23</u> in favor, <u>8</u> opposed, <u>1</u> abstention, <u>3</u> members absent or "no vote cast/received"